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## **Patient experience of hospital screening for carbapenemase-producing Enterobacteriaceae: a qualitative study**

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**Title:** Patient experience of hospital screening for Carbapenemase-producing *Enterobacteriaceae* (CPE): a qualitative study

**Short title:** Patient experience of CPE screening

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## **Abstract**

**Aim:** The aim of this paper is to explore patients' accounts of screening and being managed for colonisation with the antimicrobial resistant organism, Carbapenemase-producing *Enterobacteriaceae* (CPE), when in hospital.

**Background:** Antimicrobial resistance (AMR) has been identified as one of the biggest global health challenges of the 21<sup>st</sup> Century. As the threat from AMR grows, screening to identify patients who are colonised with resistant organisms such as CPE, is becoming an increasingly important aspect of nursing practice, in order to reduce risk of transmission of infection within hospitals. There is currently little research evidence on the patient experience of hospital management of CPE colonisation.

**Methods:** Qualitative semi-structured telephone interviews were undertaken, using a topic guide. Nine patients participated in the study. The data was analysed thematically and rigour maintained through peer review. The COREQ checklist was used.

**Results:** Two main themes were identified: 'I can't make sense of CPE', illustrating limitations in patients' understandings of CPE; and, 'I feel as if they are saying it is my fault', indicating the feelings of responsibility and blame which patients experienced.

**Conclusions:** This paper contributes original evidence to the limited literature on patients' experiences of being colonised with CPE. The findings suggest that support and information provided for patients, by healthcare professionals needs to be based on current evidence-based guidance on the nature of CPE and its implications for patient care, as well as being responsive to patients' emotional needs.

**Relevance to clinical practice:** This study has international relevance for nursing practice. As the global threat of AMR grows, the demands on health care providers to manage resistant organisms and their implications for patient care within health care settings is increasing. Enabling health care professionals to engage sensitively with patients being managed for colonisation with CPE is paramount to providing patient-centred care.

**Impact statement**

What does this paper contribute to the wider global clinical community?

- In a bid to manage the consequences of AMR for patient care, screening for resistant organisms is an increasingly important aspect of clinical practice, both within the UK and worldwide.
- This paper builds on existing knowledge about patient experience of HAIs and makes a unique contribution in relation to understanding patients' experiences of, and emotional responses to, being managed for colonisation with CPE.
- Learning from patients' accounts of their experiences of CPE screening, clinicians will be able to tailor their interactions with patients appropriately to provide effective, person-centred care which responds to their emotional needs.

## **Introduction**

Antimicrobial resistance (AMR) has been named as one of the top global health challenges of 2019 by the World Health Organisation (World Health Organisation 2019). As the global threat from AMR grows, screening for antimicrobial resistant organisms (AMROs) is becoming an increasingly important aspect of clinical practice, worldwide. The spread and presence of Carbapenemase-producing *Enterobacteriaceae* (CPE) is of particular concern within health care settings and for patients; limited treatment options are available for infections caused by this organism and the impact on patient outcomes and the economic resources required for patient care and to manage CPE are significant (Poole, George et al. 2016).

## **Background**

A recent systematic review of patient experience of health-care associated infections highlighted a small but growing literature on patients' experiences of specific HAIs (Authors, 2018); however, no included studies discussed CPE, which is an emerging organism of concern. In relation to other HAIs, the review highlighted that patients experience a range of physical and emotional responses to HAI and that the extent and nature of these responses varies by the AMRO. The systematic review also emphasises the substantive emotional and physical burden of HAIs for patients both while in hospital and after their hospital discharge. Overall, the review findings indicate that the cultural context of HAIs is complex and changing as our knowledge of different AMROs and their implications for patients' health care experiences develops as new understandings emerge.

CPE is a relatively new AMRO with guidance for its management being published within the last 5 years (Public Health England 2014, Center for Disease Control 2015, Health Protection Scotland 2016). Recent research suggests that at a general public level, CPE screening is acceptable due to the potential individual and collective benefits being greater than any discomfort caused by the screening test or personal disadvantages (Authors, 2018).

Studies to date suggest broadly, methicillin-resistant *Staphylococcus aureus* (MRSA) has taken the dominant spot as the cultural reference for HAIs among the general public, including patients, their friends and families (Andersson, Lindholm et al. 2011).

Final Author Approved Version: King, C, Grandison, T, Cawthorne, J, Currie, K  
Patient experience of hospital screening for carbapenemase-producing *Enterobacteriaceae* (CPE): a qualitative study  
Commentary and analysis of why this is proposed that it is because MRSA was linked politically within the mainstream media with a number of agendas including the cleanliness of hospitals and the state of the NHS (Crawford, Brown et al. 2008, Koteyko, Nerlich et al. 2008).

As such, with every new and emerging AMRO it is important to note that it is responded to by neither health care professionals nor patients with a clean slate. Their views of emerging organisms build on their experiences of other AMROs and also draw on wider references gleaned from the media and other sources, which are often politically infused. As such, although AMROs are a health care problem, it is important to think of and analyse it within the wider social, cultural and political frames which are shaping patients' experiences.

CPE screening commonly involves a Clinical Risk Assessment and for those identified as being at risk, a rectal swab. In the NHS Trust where the research was undertaken the policy was to screen all 'high risk' patients (in accordance with the Public Health England toolkit), on admission. In addition, all in-patients in clinical areas identified as having a high rate of CPE acquisition amongst their patients were screened once weekly, in order to identify any cross-transmission. From 2009-2016, the Trust policy was to isolate all patients who had been screened as positive for CPE. From 2016, a risk based approach to screening was adopted.

The aim of the research reported here was to explore patients' accounts of being screened for and subsequently managed for colonisation with the antimicrobial resistant organism CPE during a hospital admission.

## **Methods**

### **Study design**

The study was part of a wider mixed methods project focused on patient experience and the acceptability of screening for carbapenemase-producing *Enterobacteriaceae* (CPE) (Authors, 2018). Pope and May (1999) highlight the usefulness of qualitative methods in exploring patients' experience of health care. The use of qualitative methods in health services research has since been widely endorsed by those working in the field (Greenhalgh, Annandale et al. 2016). As such, it was decided that qualitative methods would provide the

Final Author Approved Version: King, C, Grandison, T, Cawthorne, J, Currie, K  
Patient experience of hospital screening for carbapenemase-producing *Enterobacteriaceae* (CPE): a qualitative study  
means to generate an in-depth understanding of patient experience in relation to CPE.  
Reporting of the study was guided by the COREQ checklist (Tong, Sainsbury et al. 2007) (See Supplementary File 1).

### **Ethical approval**

The study received ethical approval through the Integrated Research Application System (IRAS number (anonymised)). In addition, the study was approved by the Health Research Authority and a Capacity and Capability Assessment was carried out and approved by the Research and Development Office of the NHS Foundation Trust involved, which then granted a Letter of Access. The full study was reviewed and approved by the (anonymised) at (anonymised). All of the patients were provided with written information about the study. All of the patients who agreed to take part in the study signed written consent forms.

### **Recruitment**

Participants were recruited from an English NHS foundation trust hospital that had experienced its first outbreak of CPE in 2009 and had managed several outbreaks since. Adult patients who were hospitalised between January 2016 and December 2017 and found to be colonised with CPE during routine screening, and who were consequently managed for CPE within hospital, were eligible for study participation.

A number of postal and face-to-face recruitment strategies were used to engage with patients, with varying effectiveness. Two patients were recruited after information was posted to all of the patients on the hospital database (approximately 150) who had been screened for CPE and received a positive swab result over an 11month period. The majority of patients (7 patients) were recruited by a nurse consultant who was enrolled to identify patients who had received a positive CPE test result, to provide face-to-face information and consent patients to the study while they were still admitted to hospital.

### **Data collection**

Semi-structured telephone interviews of participants post hospital discharge were conducted by an experienced PhD qualified academic researcher not involved in clinical care (Author 1). A topic guide was used to structure the interview. Table 1 summarises topic areas covered. Interviews lasted between 30 and 60 minutes. All of the interviews were

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audio-recorded and transcribed verbatim. Nine patients participated in the study, 5 women and 4 men. One of the participants was between 20-30 years and the remaining participants were between 50 and 90 years.

### **Data analysis**

Principles recommended by Braun & Clark (Braun and Clarke 2006) were used to undertake a thematic analysis of transcribed interviews. Each transcript was read by two researchers (Authors 1 and 2) to generate preliminary concepts. Following discussion between the researchers, a coding framework was developed to allow further exploration of patient experience of CPE screening and management, within and across participants. NVivo® 10 qualitative software was used to manage coded data. Rigour in analysis was ensured through two processes: coding and interpretation of data carried out by one researcher was independently reviewed by a second researcher; and, peer review of analysis and emerging findings at meetings by all three researchers.

### **Findings**

Figure 1 provides an overview of the two main themes which were identified through the analysis of the data. These will be explored in turn in the following section (I= Interviewer and R=Respondent in quotations):

#### **Theme 1: Difficulty understanding what CPE is: ‘I can’t really make sense of CPE’**

The first theme, ‘I can’t really make sense of CPE’, relates to the challenges patients experienced in trying to understand the consequences and complexities of receiving a positive swab result, indicating patient colonisation with CPE.

Components of this theme were found to relate to the trajectory or pathway of the patient care experience from hospital admission to discharge and beyond, namely: agreeing to have a CPE screening test done; being informed of a positive CPE test result ‘on-the-move’ into isolation; communications with health care professionals about CPE; isolation and difficulty making sense of CPE management; and making sense of CPE post-discharge from hospital. These sub-categories of the theme will be explored in turn.

#### ***Consent and CPE screening***



While informal consent or permission to take a rectal swab would have been sought by the admitting nurse, the impression from patients was that this was a 'standard procedure' and not something they could or would normally refuse. Patients' accounts suggested that the information which they received about CPE at the stage of initial screening was limited in its content and depth. The short-hand explanation of CPE screening being to 'check for bugs' was commonly referred to by patients, to describe the purpose of CPE screening, as is illustrated in the quotation below:

*I didn't even know what this [swab was for]... I knew it was to check for bugs and things but I didn't know it was for something called CPE. (Patient 6)*

Many of the patients did report having a swab taken to be slightly uncomfortable and did talk about embarrassment, either their own or the nurse's embarrassment. However, for the most part, they did not feel that these emotions were problematic for themselves:

*Yeah, well originally they only did in your groin and up your nose ... now, obviously they do the rectal one as well.... Well I didn't have a problem with it. (Patient 3)*

The routine nature of the swab as 'the norm', however, meant that the information patients gleaned about CPE tended to focus on the process of doing CPE screening rather than information which would allow them to better understand what CPE is and why screening takes place:

*I: ... when they [the nurse] came to do that screen what information did they provide you with?*

*R: They didn't. They just said it was the norm and it had to be done twice a week. (Patient 7)*

Patients' accounts suggest that being screened for CPE was seen as a routine part of being in hospital by patients. As such, patients' knowledge of CPE colonisation and the purpose of screening for CPE when patients are admitted to hospital, however, appeared to be constrained by the procedure being seen as routine and an everyday part of a hospital admission.

### ***Learning about positive CPE test results***

Many of the patients talked about a rapid process of movement from a main ward into isolation after a positive CPE test result for them had been received by ward staff. Few, if any, of the patients spoke of being told the result of the screening test or having an opportunity to discuss the result by ward staff in a planned way. In the main, patients described how information provided to them about the positive CPE test result took the form of 'on-the-move' practical information while being moved by nurses from a main ward to an isolation bay, often with the promise of more information from an infection prevention and control specialist at some point in the future:

*...they said they found out half an hour before I had this disease [CPE], whatever it is I had, and they said, we've got to move you into an isolation ward ...I couldn't understand why, because I was getting well and I was walking about, I thought they were going to send me home that particular week ... (Patient 8)*

The act of moving patients into isolation meant that 'everything had changed' (Patient 6) leaving them with uncertainties about CPE and its implications for themselves and their families:

*It was a bit of a bombshell really because I'd got quite friendly with the people on the ward, we kind of encouraged each other, you know, and there was me taken from this environment where I felt fairly secure, into a single room. Infection control didn't come straight away so, I was kind of a bit...I don't know what the word is...I think I felt a bit lost, you know; a bit like everything had changed. (Patient 6)*

The description by Patient 6 of being told that she had had a positive CPE test result which required a move into isolation as a 'bombshell' goes some way to illustrating the gravitas of the experience of CPE management for patients. Again, lack of understanding of CPE and its implications at this stage of moving into isolation was evident in many of the patients' accounts.

### ***Communications with health care professionals about CPE***

For all patients, interactions with health care professionals were identified as key to their efforts to make sense of CPE, albeit with varying levels of reported success. All patients

talked about receiving information about CPE, however, this varied in relation to its content, depth, and patients' interpretations of it. Patients reported communicating with both ward staff and Infection Prevention and Control (IPC) staff about CPE. Conversations with ward-staff (doctors and nurses) were often referred to as cursory conversations from which they had gleaned a minimal amount of understanding about CPE:

*They never explained to me what it [CPE] was. It was something that they said everybody has, but occasionally somebody crops up with it and it's more active.*  
(Patient 5)

Patients often felt that they needed to be proactive and opportunistic in their interactions with ward-staff to gain more information about CPE so that they could start to process what it was and what it meant for them and their care:

*... It was more me being inquisitive than them trying to tell me. (Patient 3)*

Patients mentioned communications with IPC staff as being promised and provided but not always meeting their information needs in terms of helping them to make sense of what CPE is and what it meant for them, despite the provision of oral and written information. The time lag between being informed of CPE status and speaking to an IPC nurse (around 24-48 hours) was often problematic when patients felt in need of information more quickly. For some patients they felt that this engagement, when it did happen, had been relatively superficial and patients often felt that they could not ask the questions that they had:

*Well, somebody did come in the end to do with control, disease control or something, and discuss it, you know, and just said, well here's the leaflet. I think it was her that got the leaflet in the end, brought the leaflet and she just said what the bug was and, you know, and that was it really. (Patient 9)*

Patients also felt frustrated when they felt that ward-staff were devolving responsibility to meet their information needs about CPE to IPC staff:

*... it is a very busy ward and they often don't have a lot of time to...and I think I did say things like, what is this CPE, and they said, oh we're getting someone to come and talk to you about it. So that's not really a very good answer, is it? (Patient 6)*

In the absence of other sources of information, patients talked about referring to the internet for information which they then tried, often in problematic ways, to make sense of in relation to their own situation and family:

*Right, I found it a bit of a shock when the nurse came and said you've got this CPE, I hadn't a clue what it was about. Never been in hospital since I was in my 20s, so it was quite an experience, and then me and another young woman that were in the same ward were isolated into two side wards. There was no information given really and then a few days after someone found us a leaflet. ... But, the very first experience of it was the young woman was very computer literate, which I'm not, she went on to the computer and come across some article from...which newspaper? It was the Guardian. Oh, it was really alarming. So, at that I started to worry immediately about my granddaughter who visited with the grandchild, and my granddaughter is pregnant and I have a low immune system, so I just lay awake all night worrying... (Patient 9)*

Patient knowledge about CPE, gleaned from their interactions and conversations with health care professionals, was often uncertain and conflicting for them to understand. In the absence of explanation or discussion about what is currently known about CPE and how this can and is likely to develop and evolve, patients often felt left to try and make sense of what they were told:

*It's just a basic thing really. I mean, I know I've got this bug and I think...I think I've got it for life, I'm not sure. To me I don't know why they keep swabbing me if they know I've got it for life because they know I've got it, to be honest. ... If it was one that disappeared in time that's fair enough but I don't know why I keep having to have this test now because they know I've got it anyway. (Patient 1)*

Despite staff efforts to provide both written and verbal information, patients' accounts suggest that they often remained confused about CPE and found it difficult to make sense of what being colonised with CPE meant for their everyday lives.

### ***Being cared for in isolation***

The experience of being in isolation rooms created additional uncertainties for patients, where again they often struggled to make sense of their situation by observing the behaviours of staff and the responses of other patients. Patients talked about how health care professionals would ‘put an apron on’ when they entered the room as an indication that they were taking precautionary measures. On some occasions, however, health care professionals acted in ways that could isolate patients on more personal terms as this illustrative quotation where a patient refers to how a doctor chose not to shake her hand suggests:

*... one doctor came in one day and he didn't put them on [Personal Protective Equipment] he just said, I won't bother shaking hands with you because I'll have to go and wash my hands. (Patient 9)*

In addition to their observations of the actions of health care professionals, patients also reported on messages that they had found confusing such as being able to leave the isolation room as long as it was a for a short-time resulting in a lack of consistency in approach and confusion for patients about how CPE colonisation should be managed:

*Well, she did say to me, you know, you can go into the big ward and chat with people for short times, you know, but then when I did the nurses shooed me off and told me to go back to my room. So I was like...you know...and I did defend myself and I did say that I had been told that I can come in. ... It's quite confusing really; am I supposed to go or am I not. (Patient 6)*

Patients' accounts suggest that fellow patients also found it difficult to know how to react to, and interact with, them. Patient 6 (below) talks about her interactions with patients where she made efforts to reassure them that they would not ‘catch it’ [CPE] from her. Her interaction with one patient who just wanted to ‘get rid of’ her, as she puts it, however, illustrates the potentially marginalising effects of CPE for patients in the absence of consistent information about CPE from health care professionals:

*I just said [when talking to fellow patients] I've got this hospital bug called CPE. It doesn't affect me; I've got no symptoms, but it can be passed on through touch and, you know, it's not an air borne thing – so me talking to you here, you won't catch it. I*

*mean most people were fine about it ... there was one lady and she was quite harsh really. She said, oh well I've already got the runs, I don't need anything else. And I said, well there aren't any symptoms with this, it just lives in your gut. But I could tell she didn't want to continue the conversation, she just wanted to go – get rid of me.*  
(Patient 6)

Overall, the patient experience during being cared for in an isolation room is indicative of uncertainty of the 'rules' of CPE management. The unpredictability around the response of staff and other patients appeared to contribute to the challenge which patients experienced when trying to understand and make sense of CPE.

### ***Discharge from hospital***

Once patients had returned home they had an opportunity to reflect on their time in hospital and the impacts which CPE had had on their hospital experience and on them as individuals. Although most patients reported a sense of perspective about CPE, having had time to reflect on it since leaving hospital, it was clear from their accounts that the emotional impact and toll had been great. Often patients would recount, in great detail, scenarios where they felt confused and conflicted about what was happening to them and the implications of it for them. Once home, patients continued to mull over whether CPE was with them 'for life' or not as they made attempts to make coherent sense of CPE:

*I've been on the internet, and it's mostly stuff comes from America, there is stuff coming from this country. Like anything you take some of it with a pinch of salt, you don't believe the internet. But there's some sides talk about an antibiotic, there's other sides say there's nothing, it's just cleanliness.* (Patient 2)

This same patient then went on to talk about a place of 'resignation' that he had come to in terms of having CPE, albeit, not a happy one:

*I'm resigned to it, but I would like to think that there is something round the corner ...*  
(Patient 2)

As such, the lack of clarity experienced by most patients colonised with CPE while in hospital continued once they were discharged home and contributed to the difficulties they experienced in understanding and making sense of CPE.

**Theme 2: CPE, blame and responsibility: 'I feel as if they are saying it is my fault'**

The second key theme which was identified in the data analysis was how patients' experiences were shaped by feelings of blame and responsibility. Patients' accounts suggest that they experienced a tension related to CPE screening and its management, borne from the IPC measures implemented and necessary in order to control CPE transmission at an institutional level within the hospital, but which focused on them as individuals. This tension resulted in patients experiencing emotional reactions related to feeling personal blame for being colonised with CPE. They also felt responsibility to control their bodies, through significant management of their hygiene, in order to prevent the transmission of CPE.

***Emotional responses to a positive CPE test result: contagion and feeling dirty***

The majority of patients described a complex emotional response to having a positive CPE test result and being moved into an isolation cubicle or ward. Emotional responses included concerns relating to contagion 'I felt like I was contagious', with one patient talking about 'feeling dirty' and referring to feeling 'like a leper' (Patient 2):

*I can remember feeling dirty, I can remember feeling, oh my God, and when I told my wife she was quite upset. In fact, she was so upset that when I got home, finally got home a few days later, she'd got a bucket with water and disinfectant in it and every time I took my underwear off it was going in there. She doesn't do it anymore, but that's what she was doing at the time. (Patient 2)*

Later in the interview, the same patient went on to sum up his feelings about CPE:

*If I had anything to say about CPE would be that I do feel sometimes like a leper. I know they don't treat me like a leper, but you can't avoid feeling that way (Patient 2)*

These emotional responses existed for patients during their hospital admission when they were being cared for in isolation and continued after their discharge from hospital. These feelings of 'being contagious' yet that the circumstances that they found themselves in were not their 'fault' left patients in an emotional struggle as they tried to deal with feelings of blame. The locus of this blame was non-specific as the quotation from Patient 1 illustrates, where she talks about the circumstance as not her own fault and also not being the nurses'

Final Author Approved Version: King, C, Grandison, T, Cawthorne, J, Currie, K  
Patient experience of hospital screening for carbapenemase-producing *Enterobacteriaceae* (CPE): a qualitative study  
fault. The following example shows how patients struggled to make sense of their complex emotional responses in the absence of clear information about CPE (discussed in relation to Theme 1):

*But because of that I felt...I know it wasn't my fault but I felt like I was contagious. ... I did mention this to the nurse when she was taking me to this ward. I said, 'Well, I don't feel...I know I've got to be kept separate but I feel as though I'm contagious'. Obviously it's not her fault but that's how I felt. (Patient 1)*

The use of terms such as 'feeling contagious' and 'feeling dirty' and 'like a leper' are powerful linguistic devices which illustrate the extent of patients' emotional responses to a positive CPE test result and their subsequent care in isolation, emotions which can extend to the post-discharge period. These feelings underpinned patients' desire to disown blame and their feelings that they were being made responsible for something which was not their fault.

### ***Responsibility to keep yourself 'perfectly clean'***

Individual responsibility to control their body through hygiene measures, for example, to 'make sure you wash your hands' and 'keep perfectly clean'; and, a responsibility to protect their friends and family from CPE was a key theme within patients' accounts:

*Well, it frightened me a little bit to think that, what can I do to stop it getting more active, and it was just like I've explained before, keep yourself perfectly clean at all times. (Patient 5)*

Many of the patients referred to infection control advice from health care professionals which focused on them as individuals and their hygiene practices as having the consequence of making them feel that having CPE was their fault (as discussed above) and that it was now their responsibility to manage it and to ensure that others did not come to harm as a result of their actions or negligence as described below:

*... they say you've got to be clean, blah, blah, blah, you've got to wash your hands every time you do this, you've got to wash your hands every time you do that, you've got to clean your below, and I do that as normal. And I think to myself, well, they're as good as saying it's my fault and it's not, you know what I mean, it's not my fault,*



*it's something I've caught in hospital. But that's what it feels like sometimes, that it's my fault. (Patient 2)*

For some patients, the emotions connected with a positive CPE test result were quickly dissipated as they normalised the result using information they had received from health care professionals, for example, that it was not a problem unless they had diarrhoea. Within these accounts, however, the personal responsibility of patients to ensure that 'everybody around me would be quite safe' and to 'report back' illustrates the extent to which CPE management became the responsibility of the individual to ensure close surveillance at all times and to protect their families:

*... when they first found out, there were two nurses came in, and there was the...the ones who do the special disease and infections, and they closed the little room door, because I was in a side ward, and they told me, and my son, they had to wear protective gloves and aprons, and they explained that nobody could catch the infection unless I caught a bad dose of diarrhoea, and if that didn't happen at the hospital or at home, everybody around me would be quite safe, so there's nothing to worry about of that concern. ... And if I do have a bad dose of diarrhoea, then I must report it back to the hospital at once. (Patient 5)*

For the majority of the patients interviewed, the emotional consequences of a positive CPE test result were lasting for the duration of their hospital admission and after discharge and something for which they felt both blame and responsibility.

### ***Responsibility to prevent the transmission of CPE to family and friends***

Patients' talked about the impact of a positive CPE test result for family and friends as one of their greatest concerns. The impact for patients was very direct in relation to their relationships with their family with some patients self-excluding themselves from contact with family for fear of transmitting CPE. For family and friends, the lack of knowledge about CPE meant that they had little ability to make a judgement on its implications for themselves. A number of patients referred to MRSA, such as when Patient 1 (below) talks about 'R-S' (meaning MRSA). Patients used MRSA as a well-known cultural touchpoint to a

Final Author Approved Version: King, C, Grandison, T, Cawthorne, J, Currie, K  
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well-publicised antimicrobial resistant organism which patients drew on when trying to understand CPE:

*...they've [family] not really said anything because I couldn't tell them exactly what my infection was because I couldn't remember what the woman said because obviously I was upset at the time ...and I think they're not bothered unless it was the R-S...you know, that one. (Patient 1)*

Patient 5's reference (below) to 'a bug that was so dangerous at times' and his wife's response to CPE is an illustration of the fear that patients articulated about CPE and the responses of their family to it:

*... when it [CPE] was first explained, she [the patient's wife] was completely shocked to think that I'd got a bug that was so dangerous at times, and they said at the time, no, everybody has one, and it's just one in a thousand or one in a 100 that becomes active, and I've been one of the unlucky ones. (Patient 5)*

Some patients talked about bracketing visitors into categories of vulnerable and non-vulnerable people. This process was often related to information that they had gleaned from the internet or conversations with health care professionals. Patients had used this information to draw logic that CPE would cause few problems for the fit and healthy but could be problematic for those people who had an immune system which was in any way compromised or if for people who were elderly or young in age. Patient 9 highlights that, with hindsight, she felt that this process of categorising her friends and family in this way and deciding who should visit was 'a bit irrational'. Within the hospital context and when finding it difficult to make sense of CPE, however, this was how she had acted in order to protect her friends and family from the possible transmission of CPE. This role which patients took as guardians of their friends and family illustrates the extent to which patients felt they had been made responsible to prevent the transmission of CPE:

*I wouldn't allow her to come to the hospital, I was deprived like for a month of my granddaughter and great granddaughter. I was just too scared there was no way...and any other of my friends I was deprived of all them that has either just had*

*cancer...I would not let anyone near, the only people that come, there were lots of them, were my sons and their friends, so they were all strapping males. (Patient 9)*

As such, a sense of blame and responsibility were closely intertwined and played out in a number of ways in patients' accounts, particularly in relation to their concern about the onward transmission of CPE to friends and family.

## **Discussion**

To the authors' knowledge, this is the first study to provide an in-depth account of the patient experience of being screened and managed in hospital for CPE colonisation. CPE is a relatively new AMRO, for which screening programmes have only recently been implemented within the UK (Public Health England 2014, Health Protection Scotland 2016). Thus, developing an understanding of the patient experience of being colonised with CPE will enable health care professionals to provide more sensitive care which responds to the needs expressed by colonised patients.

A key challenge experienced by patients in this study was the difficulty in obtaining sufficient information about CPE to make sense of the implications of being colonised. The findings illustrate that from the request to screen, and onwards through the patient's hospital admission, health care staff are perceived as having limited time to explain about CPE. For patients who screen positive for CPE, our findings suggest that staff often resort to short-cut language, for example, 'you have a bug', with explanations often given briefly alongside due IPC process, such as moving a patient into isolation. There appears to be a reliance of ward based staff on 'specialist' IPC staff providing information, however, patients may have to wait some days for this information, incurring uncertainty and anxiety in the process. This finding echoes that of a recent systematic review of patient experience of a range of other healthcare associated infections and colonisation (Authors, 2018), where included studies highlighted the frustration experienced by patients in trying to get information, from healthcare professionals, which met their needs. However, whereas our participants tended to perceive this as due to time pressures on staff, other studies have reported a perceived lack of staff knowledge about the healthcare associated infection (Criddle and Potter 2006, Lindberg, Carlsson et al. 2009, Skyman, Sjöström et al. 2010). The

findings of this study suggest that patients engage in an extensive process of reworking the information they have gained. Their accounts suggest that they do this through a number of mechanisms: processing formal explanations about CPE given by health care professionals; accessing additional information from the internet; trying to make sense of CPE through how they have seen health care professionals and other patients act in relation to them in relation to either enacting IPC measures or resisting them; and, testing the boundaries of isolation imposed due to CPE. It is through this fairly complex set of processes, this study suggests, that patients try to understand CPE and its implications for their own lives and the lives of their families.

Patients' emotional responses to CPE suggest that they experience it at a personal level where they feel both blame and responsibility for it. This personalisation results in emotional fall-out for patients in terms of how they feel about themselves (dirty), how they relate to their families (self-isolation), and the pressures of the increased policing of their bodies which the measures demand (must keep perfectly clean; if I have diarrhoea I must report it). Fear over the risk of transmission can be debilitating for patients and is exacerbated by the assumption that transmission is both problematic and their responsibility to prevent. Patient accounts suggest that they feel that there is a requirement for them to police the boundaries of their own bodies and be ever-vigilant of their bodies, through hygiene measures, in ways that can be challenging in the everyday. Sociological literature on risk, explored by Lupton (1999), may help us to understand and bring meaning to these aspects of patients' experiences. Risk as a concept has been usefully operationalised within IPC clinical practice. Rarely, however, is it considered or problematised in relation to its implications for patients and their experiences of health care. The concept of risk is central to governance and how populations are monitored and controlled and how interventions are justified (Lupton 1999: 62). With increasing awareness of AMR, populations have become the focus of hygiene and other measures to try and minimise the impacts of AMROs within populations. The role of risk in governing populations and managing population health may go some way to explain why patients talked about feeling the need to be 'perfectly clean' and taking special measures to police their own bodies by refusing visits from family and friends who they deemed to be more vulnerable than others if they were to become ill or because they were already ill. The role

Final Author Approved Version: King, C, Grandison, T, Cawthorne, J, Currie, K  
Patient experience of hospital screening for carbapenemase-producing *Enterobacteriaceae* (CPE): a qualitative study  
of risk in shaping the health and illness experience of patients means that responsibility for what is a collective phenomenon caused by a complex inter-relationship of factors can be felt by individuals to be their responsibility. In addition, many of the evidenced preventative IPC measures for HAIs are individual in nature, for example, hand-washing. It should be noted that these IPC measures are well-evidenced as effective and have significant importance in terms of the delivery of safe, patient care (Storr, Twyman et al. 2017). At the same time, however, the individualistic nature of these measures can act to make patients feel hyper-responsible individually to police the boundaries of their bodies rather than to view these measures as a collective response to a social phenomenon, such as AMR.

In summary, the two major themes emerging from this study point to difficulties for patients in receiving and understanding information about CPE; and, a consequent sense of blame, responsibility, and uncertainty for patients. Findings from this study indicate the need for more effective strategies to provide accessible patient education, to ensure that patients are better informed and that their quality of life is not unduly or unnecessarily affected by CPE while in hospital or after discharge.

## **Conclusion**

Given the public health challenge of AMR, screening to identify patients who may be colonised with resistant organisms such as CPE, is becoming an increasingly important aspect of nursing practice, in order to reduce risk of transmission of infection within hospitals. Studies, such as this, which explore patient experience in depth provide the opportunity for research to inform clinical practice to ensure that patients' information and support needs are addressed.

## **Strengths and limitations**

Despite extensive efforts to recruit patients to the study, the sample size is small and, while rich and in-depth data was generated, we cannot be confident that data-saturation was achieved. While acknowledging this limitation, however, the patients who did consent to take part in the study spoke at length about their experiences providing valuable insights into patient experience of CPE screening and management, which has relevance for the

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Patient experience of hospital screening for carbapenemase-producing *Enterobacteriaceae* (CPE): a qualitative study  
design of not only CPE screening and management programmes but also AMRO programmes, more generally.

### Relevance to clinical practice

The findings of this study are particularly relevant for the design of health care professional and patient education programmes relating to CPE. These programmes require recognition of the ways in which patients make sense of CPE and how blame for CPE colonisation and responsibility to prevent its onward transmission are experienced by patients. However, it is also necessary to acknowledge that front-line staff must have opportunities to develop and maintain their knowledge of AMR in general and CPE in particular, in order to provide effective information and support to patients.

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Patient experience of hospital screening for carbapenemase-producing *Enterobacteriaceae* (CPE): a qualitative study

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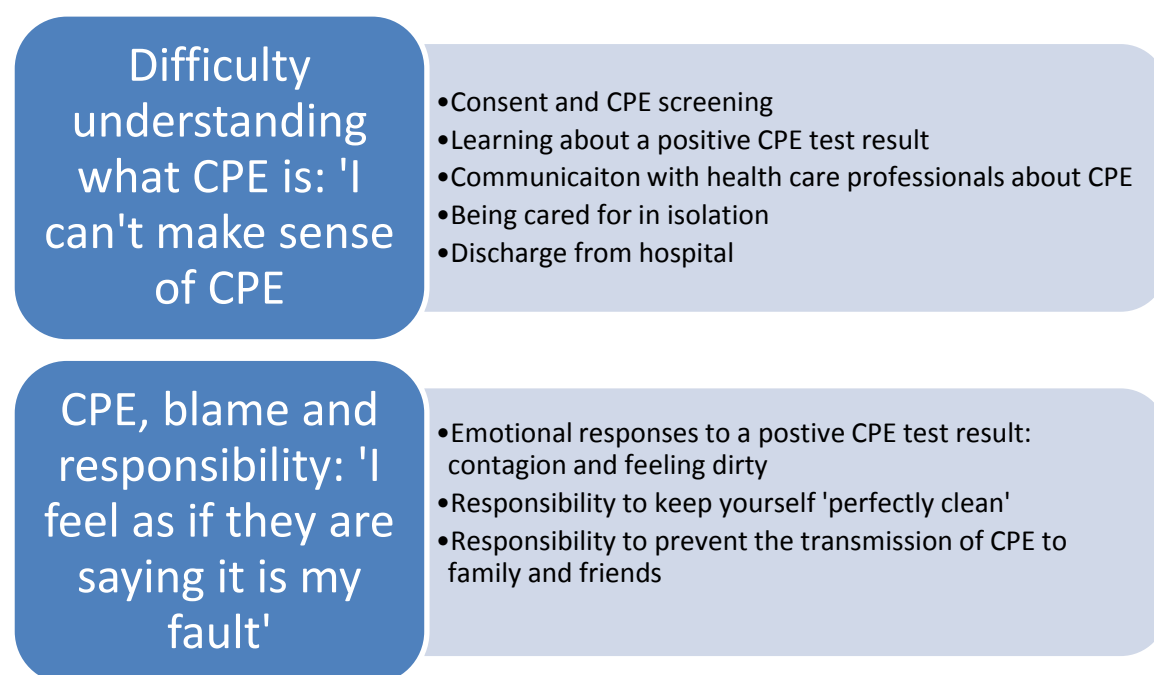
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**Figure 1: Thematic overview of findings**



**Table 1: Summary of questions covered in interviews**

|                                                  |                                                                                                                                                        |
|--------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------|
| Introductory question                            | In your own words, could you tell us about your experience of being screened for CPE while in hospital?                                                |
| Main questions about experience of CPE screening | What information about CPE screening do you recall being provided with?<br>How do you recall feeling about being screened for CPE colonisation? How do |

|                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
|--------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| and colonisation               | <p>you feel about having been screened for CPE now?</p> <p>How did you feel about having the screening test for CPE (rectal swabbing)?<br/>How do you feel now?</p> <p>Can you tell us about being told about the results of the CPE screen?</p> <p>How did you/friends/family respond to the information provided by staff about CPE and its implications for your care?</p> <p>How did you feel about being treated in a single room (isolation from other patients)?</p> <p>Having been screened for CPE, what, in your view, are the advantages and disadvantages of CPE screening from your own perspective? And for other hospital patients? The wider community?</p> |
| Questions about improving care | Have you any suggestions about how CPE screening and the management of CPE within hospitals could be improved for patients?                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| Concluding question            | Have you any other points you would like to talk about in relation to your experience of CPE screening and your care related to this?                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |